

# International Disability Rights Affirmation Conference (IDRAC)

Friday November 18, 2016 - 8:00am- 3:00pm

Saturday, November 19, 2016 - 8:00am - 1:30pm

Sojourner Auditorium, Virtual Ability Island in Second Life®

[http://maps.secondlife.com/secondlife/Virtual Ability/54/170/23](http://maps.secondlife.com/secondlife/Virtual%20Ability/54/170/23)



Speaker: Margaret Nosek and Stephanie Silveira

Title: ""

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[09:28 AM] LV (lorivonne.lustre): Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in Nearby Chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

Carolyn Carillon

LoriVonne Lustre

The following initials in the transcription record will identify the speakers:

MN = Margaret Nosek / Dhira Giha  
SS = Stephanie Silveira / Sobra

[09:30 AM] Svea Morane: Good morning everyone, and welcome to this session of the International Disability Rights Affirmation Conference.

I am Svea Morane, and go by the name Brian Kaihoi in first life.

As a connection with people with disabilities, I am a licensed teacher for students with special needs, including developmental delays and autism.

I work at Mayo Clinic, which is the world's largest integrated group practice of medicine, and the largest graduate medical training program in the world.

One of my joys is coordinating our work in Second Life, and so I am very happy to be here today.

This session is titled "Is Your Avatar A Bulletproof Vest?" and will be presented by Dr. Margaret Nosek and Stephanie Silveira.

Both Margaret and Stephanie are from the state of Texas in the United States.

Margaret holds the rank of Professor of Physical Medicine and Rehabilitation at Baylor College of Medicine

and Stephanie is almost finished with her doctoral studies in Kinesiology at the University of Houston.

Both Margaret and Stephanie have a variety of research interests, projects and collaborations,

including work with the Center for Research on Women with Disabilities, known by the acronym CROWD.

Research at CROWD has involved women with disabilities and a variety of dicey topics including

sexuality, reproductive health, bladder and bowel management, weight management, and self-esteem.

As anyone can imagine, these issues are not just physically difficult, but can be emotionally difficult as well.

Margaret and Stephanie are going to talk about feedback women have given them when they discuss some of these topics in Second Life

and some of the difficulties and successes they have experienced in trying to make related information available online and in virtual worlds.

It is my pleasure to turn the presentation over to Margaret and Stephanie, and let them lead us in answering the question "Is Your Avatar A Bulletproof Vest?".

Welcome Margaret and Stephanie.

[09:33 AM] LV (lorivonne.lustre): <transcription begins>

[09:33 AM] Carolyn Carillon: MN: Thank you so much  
I'd like to thank our previous presenter  
for an excellent and comprehensive presentation

I was impressed!  
I'd like to thank Gentle & to acknowledge Stephanie, our colleague for the last 3 ... 4 years  
She's been with us for her whole graduate experience  
She's so enthusiastic about working in SL  
and transcending the barriers those with disabilities experience  
Virtual worlds are an excellent way to break those barriers  
I'd also like to acknowledge Thomas  
Raise your hand  
There he is

I'd like to start talking about our cryptic title  
Maybe it'll become clear  
We want to talk about how the women in our studies have responded to participating in a  
virtual world  
We'll explore both perspectives -- theirs & ours  
The environment & the interventions  
I'd like to acknowledge the two studies we've conducted  
We're just finishing up now  
The second one  
is the our study on weight management for women with mobility issues  
Our other study in SL had to do with self-esteem  
This was more discussion focused  
more emotionally centered  
We talked more about interaction  
self image

Today we're going to talk about the benefits & challenges we've had in SL  
The feedback we've received  
At the end we'll get your thoughts on how YOU relate to your avatar  
How comfortable are you with your avatar  
Your perceptions of safety in virtual worlds  
Who gave us input?  
There were a total of 10 community advisors  
All women with physical disabilities  
Various types, ages  
Different racial backgrounds  
A total of 32 women participated  
We had 7 sessions  
We met once a week  
Our advisors worked closely with us throughout  
They gave us feedback  
We met regularly once a month  
They gave us feedback about how to improve the feedback  
And we'd share participants feedback with them  
The participants filled out forms after each session  
They told us what worked & what didn't work  
At the end, they had a chance to evaluate each aspect of the program

I'll turn it over to Stephanie now  
to talk about the benefits & challenges of doing this work

[09:42 AM] LV (lorivonne.lustre): SS: thank you  
It is great to be here and present on what we have learned in SL  
Some of the benefits and challenges we have learned

#### Benefits

transportation and the time burden of attending a f2f program  
Very helpful for rural participants or those who are unable to get out  
Geographically we could reach a global, not just the US  
Anonymity is very important to the participants  
Peer support and open conversation

#### Challenges

Excludes those who had limited computer or internet access  
Technological glitches  
F2F can be very rich,  
F2F is rated highest, but VW like SL rated 2nd  
over web conferencing or telephone  
Support rated as high  
Support from facilitators (M=1.13, 4-pt scale where 1=excellent)  
Support from group members (M=1.25)

What did they like best?

Social interaction and support  
Comparing SL to face-to-face program:  
Somewhat or much more convenient (95%)  
People also found it enjoyable  
Same (42%) or more (47%) opportunities for social interaction  
Same (42%) or more (26%) opportunities for lasting social connections  
Participants indicated that they would continue to interact beyond the program  
Now over to Peggy  
Addressing Physical and Program Access in SL

[09:50 AM] Carolyn Carillon: MN: We took all the feedback we got  
and threw it all into a pot  
We'd been doing this for 10 years  
We've had a lot of exposures  
We've talked to participants a LOT!  
We put all these comments into a pot and stirred it  
We call this qualitative methodology  
We weren't counting comments but sorting  
We want to figure out how do these comments come together  
We came up with 6 themes

Theme #1.

How you deal with disability

This sums it up: "It's difficult to balance whether to replicate disability and accessibility in real life versus allowing fantasy in GoWoman environments."

Here are some of the issues that had to do with replicating disability in SL or not

When you create your avatar, there's a default image

There's now a wider range but they're all able-bodied

And they're all sexy

(laughs)

Women were saying "I don't look like that!"

"I've never been that skinny"

One of our participants who is lesbian

decided she was going to take a man's body & adapt it

She thought that was kinda cool

She felt she had more accommodations to who she was

But others couldn't find anything

Then others felt liberated

to be able to create a whole new embodiment for themselves

They could adopt a different race

a different body shape

They could let go of their disability

This phrase "to leave your disability behind"

I thought that was provocative

"I've had a disability all my life but here I'm liberated"

In SL, it's hard to find the representations of disability like wheelchairs

You have to be connected to a place like Virtual Ability

It's a shift in thinking

from USING a wheelchair to WEARING one

If you want to embody yourself, you can't find things like canes

It doesn't work the same in SL

It flops around

It has limitations if you want to replicate your disability

Even wheelchairs look funny if you stand up

Your chair is stuck to your butt

It's inconsistent

Theme #2

"SL poses new kinds of challenges to movement."

Functional barriers are irrelevant

You have to decide if you want to build in things like ramps

As a political statement

We got into a big discussion about symbols of accessibility and disability

I thought it doesn't matter

Because here it's not necessary

But the advisors were VERY adamant that we needed those symbols

In terms of movement

There are other problems  
other than running into steps  
You can get trapped in a room or at the bottom of a river  
not because you don't have physical strength  
but because you're learning to navigate  
We have to do a lot of training with our participants  
to teach them how to get out of situations that seem to be hopeless  
Sometimes the computer will glitch  
and you get logged into run or fly  
and our participants are lost  
but we still hear them  
"I can't help myself ... I'm flying uncontrollably"  
Or sometimes you have an old computer or bad internet connections  
You're slow to rez  
Your avatar looks like a clown  
or it can lurch  
That happens to me  
I'll push the navigation controls and I won't move  
then I'll move a lot  
I can't stop it  
and I'm smashing into things  
This whole concept of teleporting  
that's like so Star Trek  
and I love it  
but others find it disorienting  
Finally, gestures and animations  
expressing yourself with a gesture  
In RL, we may have limitations with gestures  
In SL, my avatar is stuck in this position  
I'd love to be able to raise my arms or move around the stage  
but I'm afraid I'd look stupid  
It's a whole different set of movements

### Theme #3

"Disability affects group dynamics in SL as it does in real life, but differently."  
All our interventions were group-based  
We'd set a time for everyone to log on  
We had to set a time that worked for everybody  
They'd log on and come to our parcel of land  
We'd meet at a specific place  
meet and talk  
It was real time  
It was fun to watch the dynamics  
We needed ground rules  
Like put your mic on mute when you're not talking  
Tell us when you're done  
So we don't interrupt

Say your name before you talk  
That kind of thing  
The women who did not have their disability embodied in their avatar  
told us they felt they had to apologize  
I feel that way when I introduce myself to someone new  
I have this sexy avatar  
I tell people that I don't really look like this (laughs)  
Who am I?  
Am I the person in the wheelchair?  
Or this avatar who's so beautiful?  
It's a self-examination process  
Do you enjoy taking on this new physical persona?  
Do you use chat?  
Or voice?  
For some it's a choice  
For some it's not  
Some have a speech impairment  
Typing is easier  
We had one person who had a noisy environment who preferred to type  
That's a different way to communicate in a group  
Our people valued peer mentoring  
But here  
The avatar did not give cues that peers had disabilities  
or even that they were women  
Who's behind the avatar?  
They established that bond of trust  
They valued and enjoyed that aspect of the workshops  
Some still expressed anxiety at meeting new people  
just as they would in RL  
They expressed a need for security  
The flip side is the fear of being attacked or intimidated  
or getting stranded  
Some would really get alienated from not being in full control of their avatar  
It was disorientating for some  
It was difficult to communicate  
But for others who had visual impairments in addition to physical limitations  
They felt this was an equalizer  
Since nobody here had the ability to read a facial expression

#### Theme #4

"Exercise in SL has effects in real life."

I want to research this more  
This is called the Proteus Effect  
where a virtual experience has a corresponding effect on the physical body  
When their avatar exercised  
they had a higher breathing rate  
When their avatar meditated

their body relaxed  
One woman told us that if she could feel this good dancing in SL  
Imagine how they'd feel in RL  
We need to explore this  
In medicine it's the placebo effect  
I don't like that  
But what they're talking about is the power of the imagination  
We know all about affecting your body with your mind in negative ways  
So why can't we do this in positive ways, too?  
SL gives you the opportunity to practice new behaviours  
I preach this but I don't do it  
What if everyday I worked out every day in our SL exercise area  
We've got kickboxing, weightlifting  
What if I started my day by exercising my avatar?  
What would happen?  
What if I made a routine  
of just going to another island  
and making one new friend every week?  
Just for the fun of it  
What would happen?  
That would be such a wild new experience  
I would NEVER do that in RL  
I do have some social groups  
but I spend 14 hours a day parked in front of my computer  
I'm really focused on my work  
The idea of making one new friend each week  
That would be fun  
SL allows you that opportunity  
Even though it's happening in a virtual world

#### Theme #5

"There can be a physical disconnect between the virtual body and real-world body."

This is the opposite of #4  
You can create a new identity like I did  
A new behavioral identity  
In RL you may be shy  
Here you can try out new behaviours  
If you tend to be stubborn in RL  
You can experiment with your relationships here  
Do you use your avatar to insulate you?  
Does it protect you?  
Or does it isolate you?  
Is it liberating?  
Is it isolating?  
There are comments on both sides of that  
We did have women who applied to participate  
When we trained them



They felt totally weirded out  
They said they couldn't relate  
They withdrew  
But others found it was so cool  
They felt so relaxed  
They loved the fantasy of it  
We're talking about women  
Women are very grounded in reality  
Because they have to deal with the needs of their family  
For some women it's hard to let go of that  
But for men  
Who are the predominant users of video games  
They have an easier time of getting into the fantasy  
Some were willing to experiment  
Some came back after the interventions were finished  
Who said they wanted to explore SL more  
But time was a factor

#### Theme #6

Can communicate what they choose to relating to disability  
You can communicate whatever you want to about your disability  
Many appreciated the privacy of our island  
They didn't have to share anything they didn't want to share  
They didn't worry about that awkwardness of the first contact with someone new  
You know when some people who speak too loud  
Because they assume you can't hear if you're in a wheelchair  
Or how some bend down to your eye level  
But it's different with avatars  
And then there was the ability to talk about difficult topics  
“...I felt like we were able to share more freely than we might have done without the avatar  
or SL.”  
This environment gave them the privacy and confidence that they could discuss very  
sensitive topics

So finally I want to open it up  
to ask you  
How do you regard your avatar?  
Is it a bulletproof vest  
or a magic carpet  
or both?  
Do you feel more or less open to discussing dicey topics?  
What are your thoughts?  
Let's open the floor

[10:16 AM] Fidget (fidgetswidgets): My avatar is magick! I can constantly change it. I can wear my mind or hide my thoughts as I see fit. I LOVE my avatar.

[10:17 AM] Ruby Vandyke: I feel more open to discussing topics. I love my SL and my avatar. I identify strongly with my avatar to the point I've adopted her name as my RL nickname

[10:17 AM] LV (lorivonne.lustre): <<me too Ruby >>

[10:17 AM] GraceyLaceyLou: "My avagaw awwowf me go be abwe go geg oug of my mind and abwe go be whag i wang wigh oug now one making me feew afhamed of myfewf!"

[10:18 AM] Ruby Vandyke: yes, I introduce myself as 'Ruby' in RL now, the funny part is - Ruby gets more phone calls and snail mail than my RL self {laughing}

[10:18 AM] Gentle Heron: I respond to "Gentle" in physical worlds.

[10:18 AM] Mook (mook.wheeler) responds to Mook in RL too :)

[10:19 AM] Gloriejoy (joycie.string): I am who I am in both worlds...the only difference is that my avatar does not have asthma!! Yay!!

[10:19 AM] iSkye Silverweb: I'm known as iSkye in both worlds, nicknamed "Skye"

[10:20 AM] Eme Capalini: I answer to my SL name in RL.

[10:17 AM] Leandra Kohnke: We actually published on this. We called the human avatar pair a Havatar.

[10:17 AM] Svea Morane: Just as a reinforcement of your feedback... in our clinical trials, specifically in cardiac rehab, we have gotten the same feedback from our patients.

[10:18 AM] Mook (mook.wheeler): COMMENT: I would like to send Dhira and Sobra several academic presentations (delivered in SL) on the mirror neuron and 'backformation' effects SecondLife enables, both of which relate directly to their research on the Proteus Effect.

I also have the academics' names and contacts for you

[10:19 AM] Carolyn Carillon: MN: This is our contact info on the screen now

[10:19 AM] LV (lorivonne.lustre): crowd@bcm.edu

[10:20 AM] LV (lorivonne.lustre): mnosek@bcm.edu

[10:20 AM] ThomasM Torok: Margaret - you might give the reference where some of this work is published in the literature

[10:20 AM] Shyla the Super Gecko (krijon): Can I voice a comment

[10:20 AM] LV (lorivonne.lustre): Shyla: my avatar is small and friendly and open to listening It also claims to be super!

Behind it is someone very strong

I find that sometimes people assume that small avies are not as strong. This is not so

[10:21 AM] Carolyn Carillon: MN: Interesting

I'm kinda the opposite

And I don't know why

In RL I'm really obnoxious (laughs)

In SL, I'm much more respectful and compassionate and insecure

because I don't feel like I move around very well

I'm not expert at moving my avatar

I don't have the time to invest in learning

If I could just learn how to give a high five

that'd be cool

But I haven't figured that part out yet

I admired all of you who have beautiful outfits

My inventory is a mess  
I can't figure out how to find anything  
Acquiring clothes I like takes SO MUCH time  
HOURS

Trying to find stuff

So I'm much more insecure here

So we're the opposite, Shyla

[10:23 AM] Shyla the Super Gecko (krijon): VAI has folks who do inventory organization workshops once in a while, that might help...

[10:23 AM] Svea Morane: Perhaps we need Stephanie's perception of your first life self ;)

[10:24 AM] Carolyn Carillon: SS: I'm the same here & in RL

[10:24 AM] LV (lorivonne.lustre): SS: I think that I carry over pretty well. When I do something silly in SL, I just laugh it off -- like I do in RL

Although I would be a bit more concerned if I was suddenly naked in RL!

[10:24 AM] GraceyLaceyLou: "may i pweafe voice a commeng!"

[10:25 AM] Carolyn Carillon: GRACEY: one thing I love

In RL I can't drive

but in SL, I can drive

[10:25 AM] Gentle Heron: Good for you Gracey

[10:25 AM] Carolyn Carillon: MN: I would love to try that too

I can only drive my wheelchair

And not very well

[10:25 AM] Gentle Heron: QUESTION: Why do you consider using ramps in SL instead of steps to be a political statement? Couldn't it be a form of modeling best practices for RL?

[10:26 AM] Carolyn Carillon: MN: I like that

I think you're right

It could be

Universal design is a mindset

It's a throwback to the old days to even have steps

You're right

When they say all kinds of things

About the way things were

Those kinds of statements

of the way things were

are really saying

Let's make everything exclusive

Let's leave people out again

You're right

We have to eliminate that from our consciousness

We need to let everybody in

That's a really good statement, Gentle

How can we promote that?

Maybe like you have here

Virtual Ability is completely accessible

And there's nothing unusual about it  
There's no reason why this couldn't be done in RL  
[10:27 AM] Pecos Kidd: Look at the design of this auditorium, for example.  
[10:27 AM] Gentle Heron: I'd like Eme (EC) to speak to that please.  
Eme headed the build team for this island!  
[10:27 AM] LV (lorivonne.lustre): EC: I was on the build team  
Part of the process was to model best practice, but to look completely normal  
There are no signs that say this is done this way for accessibility. There are no steps  
anywhere out of respect for universal design  
It was part of our mindset. That you can build with respect and to show how it can be done  
[10:29 AM] Carolyn Carillon: MN: Brilliant  
I love it  
All of SL should be like this  
I admire you for doing that  
One more question I'd ask  
You all have people you've tried to bring into SL  
How do you help them overcome that fear?  
Of being in an environment that could be disorienting?

[10:30 AM] Gentle Heron: QUESTION: How hard is it to find academic colleagues to work  
with you inside a virtual world environment? How hard is it to convince people with little  
computer experience to try out a virtual world as a research subject?  
[10:30 AM] Carolyn Carillon: MN: Really it's all or nothing  
I find my colleagues have an open mind  
Or are absolutely opposed  
There's no middle ground  
If they're not computer savvy it's a moot point  
They don't have the tech available to do it anyhow  
If they did have it they'd be open to it  
I deal with lots of folks  
The highest tech they have is a cricket phone that can't even access the internet  
There's a whole level of society that can't access tech  
So we have to help them tap into what's available  
They're open but it's about access to resources  
It's shocking among academics  
Some people just have closed minds  
They can't get out of the 20th century  
They're not open  
It's sad

[10:30 AM] Gentle Heron: How do we help people get over that initial fear? (question to the  
audience!)

[10:32 AM] iSkye Silverweb: Even if they are computer savvy, many make assumptions  
about 'oh, I know what to do' and it can be an eye opener but it can also be a very liberating  
experience  
Once you get them IN here, they see the possibilities

[10:32 AM] LV (lorivonne.lustre): SS: as far as using SL -- we used to use it more in our department even with course work

[10:33 AM] Svea Morane: My experience is that the barriers, responses and mindsets for using virtual worlds with colleagues and the general public is about identical to when I was bringing the Web into our organization back in 1980.

[10:33 AM] LV (lorivonne.lustre): SS: it is not as much right now.

[10:33 AM] Carolyn Carillon: MN: the younger generations

It's a no brainer

They're into technology

So it's no problem for them

It's the middle and older generations

They're hard to convince

And then academics

have the excuse

"I'm too busy"

I don't have much patience for people with closed minds

It's a fear

I get concerned when we have participants who are trying hard to learn

and then they'll go off and get stuck in a bush or in trees

and they're screaming for help

they're really afraid

They feel out of control

We do everything we can

Stephanie is a facilitator for those people

She does everything

She calls on the phone

She texts with them

to help them calm down

It's been pretty successful

They come back

and gain confidence

Have you had experiences of talking people down & allaying their fears?

We've even got one co-investigator who will not go off island

because she doesn't want to be assaulted

What are you talking about?

Just click the home button!

[10:35 AM] Pecos Kidd: Teach them how to "teleport home" whenever they are stuck or lost.

[10:35 AM] Carolyn Carillon: MN: But she's so afraid of exploring

She has to be in control

That makes her a great researcher

But wow

She's afraid of the environment

[10:36 AM] Gentle Heron: It also means you created a safe environment for her, which is good.

[10:36 AM] Carolyn Carillon: MN: that's true

I guess that's progress

We've dragged her kicking and screaming into the technology

So we have made some progress if she feels safe

[10:36 AM] Gentle Heron: One step at a time.

[10:37 AM] iSkye Silverweb: it does take time, there is a learning curve but there is also the safety factor

[10:38 AM] Mook (mook.wheeler): there is always fear in the beginning with something new, but that will fall away as she gets in more practice and experience

[10:37 AM] Carolyn Carillon: MN: Thank you all for your comments

Feel free to contact us

Go to our site

Check out what we've done

We just got some new grant funding to expand our research

We're doing the GoWoman project with both men & women with spinal cord injuries

So we're plowing ahead

My goal is to make these interventions available here in Virtual Ability Island

I need your help in helping everyone appreciate this wonderful world

[10:38 AM] Gentle Heron: Thank you Dhira and SLSlivei. Your work is wonderful to know about. A good use of the virtual world.

[10:38 AM] LV (lorivonne.lustre): SS: thank you for having us and for all the feedback. It was great.

[10:38 AM] LV (lorivonne.lustre): <transcription ends>

[10:38 AM] Gentle Heron: During our break, please consider visiting the displays and exhibits on Healthinfo Island. Many relate to this presentation about l'Arche.

Displays:

The l'Arche Story <http://maps.secondlife.com/secondlife/Healthinfo%20Island/196/157/23>

The History of the Independent Living Movement

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/190/179/24>

Why is Community Important to People with Disabilities?

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/172/154/22>

Exhibits:

Jean Vanier on Disability

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/113/78/24>

What Defines Community

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/96/41/26>

The Role of Organizations for People with Disabilities

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/51/27/28>

Jean Vanier on Community

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/25/25/30>

What do you call people with disabilities?

<http://maps.secondlife.com/secondlife/Healthinfo%20Island/21/63/32>